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OCTOBER TERM, 1998

**TOMMY OLMSTEAD, COMMISSIONER OF THE
DEPARTMENT OF HUMAN RESOURCES OF THE
STATE OF GEORGIA, ET AL.,**
Petitioners,

v.

**L.C. AND E.W., EACH BY JONATHAN ZIMRING, AS
GUARDIAN AD LITEM
AND NEXT FRIEND,**
Respondents.

ON WRIT OF CERTIORARI TO THE
UNITED STATES COURT OF APPEALS
FOR THE ELEVENTH CIRCUIT

**AMICI CURIAE BRIEF OF
NATIONAL MENTAL HEALTH CONSUMERS'
SELF-HELP CLEARINGHOUSE, ET. AL.,
IN SUPPORT OF RESPONDENTS**

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James Conroy et al., <i>A Matched Comparison of the Developmental Growth of Institutionalized and Deinstitutionalized Mentally Retarded Clients</i> , 86 <i>AM. J. MENTAL DEFICIENCY</i> 581 (1982)	24

Michael J. Kennedy, <i>Turning the Pages of Life</i> in J.A. Racino, et. al., <i>HOUSING, SUPPORT, AND COMMUNITY: CHOICES AND STRATEGIES FOR ADULTS WITH DISABILITIES</i> 206 (1993)	11
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Aileen B. Rothbard & Eri Kuno, <i>The Success of Deinstitutionalization: Empirical Findings from Case Studies on State Hospital Closures</i> , <i>J. INT'L LAW & PSYCHIATRY</i> , January 28, 1999, at 3-4	24
Aileen Rothbard, et al., <i>Service Utilization and Cost of Community Care for Discharged State Hospital Patients: A Three-Year Follow Up Study</i> , <i>American Journal of Psychiatry</i> , December 9, 1998, at 2	18
OTHER AUTHORITIES	
A Service Development Plan for a Comprehensive System of Public Mental Health Care in Compliance with the Orders of the Court in <i>Dixon v. Sullivan and Dixon</i> , July 1991 (Approved and ordered on January 27, 1992, U.S.D.C. for the District of Columbia, Civil Action 74-285 (AR)).....	20
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K. Charlie Lakin and Mary Hayden, Final Report to the Health Care Financing Administration: An Evaluation of Implementation of the Medicaid Community Supported Living Arrangements (CSLA) Program in Eight States (1996).....	20
Zana Marie Lutfiyya, Center on Human Policy, <i>Reflections on Relationships between People with Disabilities and Typical People</i> (Aug. 1988)	23
State of Alabama, Department of Mental Health and Mental Retardation Five Year Plan FY 93-94 to FY 97-98.....	20
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INTEREST OF AMICI CURIAE¹

The National Mental Health Consumers' Self-Help Clearinghouse is a national technical assistance center established in 1986. It is run by and for people who are consumers of mental health services and survivors of psychiatric illness (known as consumers/survivors). Its mission is to promote consumer/survivor participation in planning, providing and evaluating mental health and community support services, to provide technical assistance and information to consumers/survivors interested in developing self-help services, and advocating to make traditional services more consumer/survivor-oriented. As with all of the other amici, the Clearinghouse has an interest in helping people with mental illness live to their full potential as active members of the community.

The Alaska Mental Health Consumer Web is a resource for mental health consumers. All of its efforts are aimed at promoting recovery. Among its many activities, the group organizes consumer support groups, has been effective in changing mental health policy, and fights the stigma of mental illness through information and education.

C.H.O.I.C.E.S. in Georgia (Consumers Helping Ourselves with Information, Communication, Empowerment and Support) is an advocacy organization of consumers/survivors dedicated to ensuring consumer choice. Its current initiatives include working to promote (1) the establishment of extensive and varied community resources and services, especially

¹ The parties have consented to the filing of this brief under S.Ct. R. 37.2, and their letters of consent have been lodged with the Clerk of the Court. Pursuant to S.Ct. R. 37.6, amici state that counsel for a party did not author this brief in whole or part and that no one other than amici, their members, or their counsel made a monetary contribution to the preparation or submission of this brief.

peer-run services; (2) the use and acceptance of advance directives; (3) early intervention in helping people diagnosed with mental illness and in providing them with information and options; and (4) societal understanding and acceptance of diversity.

Contac is a national technical assistance and resource center for consumers/survivors and consumer-run organizations across the United States, promoting self-help, recovery and empowerment. Contac was developed utilizing research on ideal consumer self-help programs, successful consumer-run programs, community support service philosophy about service delivery, descriptions of mature mental health systems, and management and leadership skills.

The Madness Group operates a decentralized electronic forum and distribution device for exchanging information about methods for advocating social change. The group also distributes resources of use to people who have psychiatric histories.

The Mental Health Empowerment Project, Inc., is a not-for-profit corporation that starts self-help and advocacy groups for mental health consumers and provides training in psychiatric rehabilitation. It operates in several states with state contracts or managed care public sector contracts.

Pennsylvania Protection and Advocacy, Inc., is the Governor's designated protection and advocacy system for persons with mental illness. The majority of its Mental Health Advisory Board members are individuals who have experienced both institutional and community-based mental health services, as have members of its Governing Board.

Plusabilities is a Georgia-based consumer/survivor-owned and -operated business. Plusabilities contracts with public mental health/mental retardation/substance abuse agencies to conduct consumer and family satisfaction/service evaluation/outcome measurement surveys, and provide peer

support to consumers/survivors moving into the community from hospitals or other congregate settings.

United Self-Help is a consumer group in Hawaii that works to keep people out of the hospital by promoting attendance at support groups. Its members support the concept that community-based services, including peer-run services, are the most effective way to promote recovery in people with mental illness.

Well Mind Association of Minnesota's mission is to expand treatment options for people diagnosed with mental illness, to provide information about integrative health care for these individuals, and to encourage their self-empowerment.

Sally Clay is an individual who has experienced manic-depressive episodes (including some 19 hospitalizations) since 1962, and has worked as a peer organizer and advocate for over 18 years. She is currently working as a systems manager or peer consultant with two grants from the Substance Abuse and Mental Health Services Administration, one for Consumer-Operated Services and one for Women and Violence. She credits her recovery to the services and supports she has received in the community.

Margaret M. Geary, J.D., a mental health consumer, is a Massachusetts attorney and member of the Supreme Court bar practicing in the area of mental health law. She has represented many people who have been committed to state institutions and is a strong advocate of the position that people with mental illness can be served most effectively in the community.

Steven LaMaster, M.S., is a rehabilitation practitioner for ResCare, Inc., an agency that provides psychiatric rehabilitation services, including a wide array of residential supports, to people who experience difficulties in living, learning, working, and socializing. The agency supports individuals'

right to self-determination regardless of the symptomatology that they experience.

Barbara Lee, Ph.D., is a consumer of mental health services and a clinical psychologist and policy and services researcher, working with people who also have experienced severe mental illness. As a professional, she has seen people who had spent long periods in institutions, with little or no progress there, make a successful transition to living in the community, with the appropriate services and supports.

Alexander R. McNaught was diagnosed with schizophrenia 22 years ago. Except for brief hospitalizations totaling two months, he has lived and continues to live successfully in the community.

Laura McRae, who has been repeatedly hospitalized for mental illness, lives and works in the community. She characterizes her hospital experience as "warehousing," with very little in the way of treatment or activities, and the absence of power over her own life.

David Shaver is executive director of Consumer Support Services (CSS), which operates a mental health community center, funded by the State of Florida Department of Children and Families and the City of Jacksonville. CSS has a membership of over 300 persons with mental illness, approximately 30 percent of whom have been long-term residents of state mental hospitals. CSS supports the development of community placements and supports for people in institutions.

Laura Van Tosh is a person with a psychiatric disability who has been institutionalized in the mental health system and has benefited from community-based programs. She has participated in psychosocial and vocational programs and has used the Americans with Disabilities Act to secure reasonable accommodations in employment. Ms. Van Tosh is now an advocate and a consultant in the health care field. She

credits her recovery to caring professionals, self-help, advances in treatment, and the opportunity to live in the community.

SUMMARY OF ARGUMENT

This brief will examine the critical relationship between community services and the integration mandate at issue in this case. Amici are individuals and organizations of individuals who have experienced both institutional and community-based mental health services. Through some of our individual stories and supporting professional literature, we will document that community-based services provide myriad opportunities for interaction between people with and without disabilities, promote recovery, and lead to a more enjoyable, fulfilling life.

The state of Georgia and its amici argue that this Court should give discretion to the states to decide where and how to serve people with disabilities. They ignore, however, that their discretion can and has resulted in people with disabilities living under conditions of great and unnecessary restriction, with limited contact with non-disabled individuals and very little personal freedom for many years. Political pressure, bureaucratic inertia, job concerns of hospital employees, neighborhood resistance and other factors have too often taken precedence over the rights of people with disabilities who could be served in the community. This is particularly egregious given that community-based services are less expensive than institutional care.

The integration mandate of the Americans with Disabilities Act requires that people with disabilities be allowed the same freedoms that people without disabilities take for granted: the ability to see family, friends, neighbors and co-workers; to go to church, the movies, shopping, the library or simply to go outside; to hold a job, enjoy a hobby or

volunteer for a cause. It is these personal liberties that are at stake in this case.

We begin with personal accounts illustrating the benefits of living in the community as opposed to institutional care. It is important to note that none of the people whose stories are told below were released from an institution because they had "recovered." In every case—and this is typical of most people who have spent significant periods of time in an institution—they were released either due to changes in policy, or through their own efforts or those of their advocates.

After recounting these stories, we describe the array of services that may be found in a community-based mental health system. Not every person with a disability will need the same kinds of service. Each of the individuals whose lives we describe receive some of these services according to their needs. In this section of the brief, we give a more technical description of these services and conclude with a review of the professional literature confirming the benefits of integrated services.

ARGUMENT

I. PERSONAL ACCOUNTS OF THE BENEFITS OF INTEGRATED SERVICES

For someone who has never been in an institution, the stark contrast between community and institutional life is difficult to imagine. But those who tell their stories below, or whose stories are told by others, don't have to imagine; all have spent years living in institutions. Now, each is living successfully in the community. These stories are not atypical. They represent personal accounts of the well-documented positive outcomes of integration: the ability to be part of a community which includes people with and without disabilities; greatly increased fulfillment and productivity as workers and volunteers; and more rapid recovery as an individual

makes choices, learns skills in a natural environment such as a home or a workplace, and forms meaningful relationships.

A. Jane D.

Jane D., a woman in her fifties, had lived in the state hospital for many years. Jane experienced significant reductions in physical injury and neglect when she was discharged to a smaller, more integrated setting. Her recent discharge into the community radically improved her life.² According to her advocate,

this lady had taken so many falls in the state hospital and had broken her leg so many times, they thought they would have to amputate. She was incontinent and 'gray': she had gray hair, gray skin and a gray look. I never saw her move; she was parked in a chair all day, every day. She was locked in a dining room, and had no independent access to a bathroom. They had to sit in the locked room and wet themselves.³

When Jane was released into the community, it was thought that she had dementia, so she was at first placed in a restrictive program. However, very soon she was moved to an unlocked group home. After this transition, her advocate

did not recognize her when I went to visit her. She was outside, beautifully dressed, and she talked to me. In a year and a half [that I saw her] at the state hospital, she never talked. Now she was alert and lively. The staff said

² Telephone interview with Diana Carra Haugh, Advocacy Specialist, Pennsylvania Protection & Advocacy (February 11, 1999).

³ *Id.*

she hasn't been incontinent since two weeks after she came here. Obviously she now lived in a place where she could get to the bathroom and had fun, interests, stimulation; she had decided to go on living. There were no more falls [because] her medication was drastically reduced. She likes to walk, she participates in church groups, she likes to go shopping. Her favorite thing is going to flea markets. She has friends. Try to picture a gray, quiet, frail woman who didn't engage or express anything. Now picture someone with a big smile, beautifully dressed, striding down the lawn.⁴

B. James Price

James Price, now in his mid-40s, spent much of his life in an institution, but now has achieved independence in his own apartment and fulfillment in volunteer activities and family relationships. Mr. Price spent 10 years of his youth in Pennhurst State School. Later, as an adult, he was in Norristown State Hospital for two or three years. He was subsequently admitted to Philadelphia State Hospital, and spent five or six years there. He described the conditions at the hospital. "It was hard living there," he recalled. "I had to stay in a day room and wasn't able to get out. We had a dormitory with eight to ten people. I got in trouble there a lot. They would put me in seclusion and restraints and give me needles."⁵

For the last eight years, however, he has lived in his own apartment in Philadelphia, and he enjoys his freedom. He worked for the Philadelphia Department of Sanitation for five

⁴ *Id.*

⁵ Telephone interview with James Price (Feb. 9, 1999).

years. Now he lives off what he receives from Social Security Disability Insurance. He contrasts his life in the hospital to his current life in the community:

Now that I am out, I don't smoke or drink anymore. I go to Cocaine Anonymous meetings and serve coffee. I help out at Zion Baptist Church stuffing envelopes. A deacon gets me to help him move disabled people into apartments. I go to the park, do my own shopping and cooking. I see my mother, my brothers and sisters. I go to movies sometimes on Sundays with one of my friends. Sometimes my niece comes over and spends the night. She's eight or nine years old. I make sure she eats: I cook for her or take her to McDonald's or Burger King. That's fun.⁶

C. Michael J. Kennedy

Michael Kennedy's personal account reveals that institutions, in their isolation from public view and low staffing, tend to allow more abuse and neglect to continue. However, his story also shows the myriad of opportunities for a productive life in the community. He is married, owns his own home, and works as an advocate for people with disabilities at Syracuse University's Center on Human Policy.⁷

Born with cerebral palsy, Mr. Kennedy was placed in an institution in New York State at the age of five. He was transferred from there to another institution, and from there to a third. He finally won his release when he was 21.

⁶ *Id.*

⁷ Telephone interview with Michael Kennedy (Feb. 11, 1999).

His years in the institution were marked by neglect. He attended a segregated school on the grounds of the state institution where

all we did was watch 'Sesame Street' on TV every morning. We put pegs in a peg board for the other half of the morning. Then we went to lunch, and then we took naps until it was time to go back to the unit. When I outgrew my braces, they took them away and never ordered me any more. My mother used to give me physical therapy at home; they stopped that, as a punishment.⁸

As a result of his educational neglect, he had no formal education; he went back and got his General Equivalency Diploma when he was 32 years old. He further describes very poor conditions in the hospital:

The hallways of the institution were dark and dingy. It smelled like urine and feces; although you didn't see any, it smelled like it because it was embedded in the tiles and the floor. People would lay around naked half the time. The staff members who cared didn't stay for very long. They couldn't stay and watch what was going on, which included the use of cattle prods and ammonia sprayed in the eyes as punishment.⁹

After many years in institutions, Mr. Kennedy heard about a supported apartment program and advocated to receive services in the community. In an article about his experiences, he wrote, "What I liked most was that the apart-

⁸ *Id.*

⁹ *Id.*

ment was in the community. I was viewed as belonging to the community and could experience being around people without disabilities."¹⁰

Michael Kennedy is one of many individuals who have spent significant periods of their lives in institutions and who was able to make a successful transition back to the community. His life now has much in common with the lives of his neighbors.

My wife and I both work; we are very active members of our community and our church. My wife has cerebral palsy as well; she also uses a wheelchair. She's a vocational rehabilitation specialist.

We're very well known and respected in our neighborhood. We enjoy going away on vacation, we go to movies, we do the same things anyone would do. In an institution, you didn't get those luxuries. If you did get to go out of the institution, you went in groups. You couldn't even strike up a relationship if you wanted to. Freedom means a lot—that I am somebody regardless of what my limitations are. What I advocate for is that people like me can live a normal life, regardless of their disability. Part of my job is to make sure that they get a fair shot.¹¹

¹⁰ Michael J. Kennedy, *Turning the Pages of Life* in J.A. Racino, et. al., *HOUSING, SUPPORT, AND COMMUNITY: CHOICES AND STRATEGIES FOR ADULTS WITH DISABILITIES* 206 (1993).

¹¹ Telephone interview with Michael Kennedy (Feb. 11, 1999).

D. Bernie S.

Bernie's living situation perhaps best illustrates the difference between a hospital and a home. At age 21, Bernie started hearing voices. His parents took him to a psychiatrist who diagnosed him with paranoid schizophrenia and strongly advised that he be institutionalized. After a year and a half at the Institute of Pennsylvania Hospital, when his insurance ran out, he was transferred to Haverford State Hospital, where he stayed 22 years.¹²

Bernie moved into a supervised group home in June 1998. He lives with four other men in a small white house run by Elwyn Institute, in Elwyn, Pennsylvania. There are several staff during the day and one person who remains on duty during the night after 11 pm. His mother explains the change in his opportunities and life as follows:

They live in a family atmosphere; it's not institutionalized. Bernie and the other residents cook together; they help the staff to prepare meals; they buy their groceries. The staff and the residents sit at the dining room table and eat their meals together. They watch T.V. in the living room or play games—Trivial Pursuit, Monopoly, you name it. Each person has his own room. They have learned to wash and dry their own clothes It is not the same to live in a hospital as to live in a house surrounded by beautiful grounds, and flowers, which they take care of. They live their lives

¹² Telephone interview with Aimee S., mother of Bernie S. (Feb. 11, 1999).

like I live my life. I couldn't ask for anything better.¹³

Like many of the others described herein, Bernie now participates in numerous activities that enrich his life and allow him to interact with people without disabilities. For example, he goes on trips to attractions such as the Arboretum, Ridley Park and the Philadelphia Museum of Art; an instructor teaches him T'ai Chi and a pastor comes every two weeks to talk to him and other residents. Most importantly, Bernie has begun initiating conversations. For 22 years in the hospital, he talked very little, if at all. Now, when he and his mother go to a restaurant, he will comment if she is not eating. Recently, his mother noted that Bernie had spontaneously commented that she had cut her hair. In her words, "I almost dropped dead. That's something he would not even mention before. Now he is much more alert to the environment because the staff is constantly stimulating him and the other residents."¹⁴ The small ratio of staff to resident allows for more innovative programs and good guidance. Their assistance has led to an enormous difference in his quality of life and ability to socialize with other people.

¹³ *Id.* A similar account can be found in the non-fiction book written by reporter Michael Winerip, who followed the lives of residents of a mental health group home in Glen Cove, New York. One of the residents, Fred Grasso, had schizophrenia and had been living in a two-hundred-bed facility which had been cited for numerous health and safety violations. His mother expressed her great relief at the lovely group home, which had a living room with a fireplace, a dining room, bedrooms and a well-stocked kitchen. M. Winerip, 9 HIGHLAND ROAD 72-74; 101-104 (1994). "You don't know what this means to me," Mrs. Grasso said, her eyes filling with tears once more. "You don't know." *Id.* at 74.

¹⁴ Telephone interview with Aimee S., mother of Bernie S. (Feb. 11, 1999).

E. Margaret Donahue

Margaret Donahue describes the increased privacy, opportunity for making her own choices and reduction of symptoms that occurred when she was provided with integrated services in the community.¹⁵

Ms. Donahue, who is diagnosed with schizophrenia, spent most of her life in institutions. These include Philadelphia State Hospital and Norristown State Hospital. She now lives in Willow Grove, Pennsylvania, in a house she shares with two other women, both of whom were also patients at the state hospital. The house is a "supported living" residence, with round-the-clock staffing.

She has her own bedroom, and relishes her privacy. In her words:

There's a lot of things you can do living in the community, like go up to your room if you want to be by yourself. In the hospital, there were a lot of people. We had dormitories, six people in each.¹⁶

She has also experienced a reduction in her symptoms and, thus, freedom from restrictive and sometimes painful measures such as physical restraints. In the hospital, she reported, she spent a lot of her time in restraints because of

¹⁵ Telephone interview with Margaret Donahue (Feb. 10, 1999).

¹⁶ *Id.* The indignities and lack of privacy in the hospital are also documented in an autobiography by Professor of Psychology Kay Redfield Jamison. K. Jamison, *AN UNQUIET MIND* (1995). She writes, "My psychiatrist repeatedly tried to persuade me to go into a psychiatric hospital, but I refused. I was horrified at the thought of being locked up; being away from familiar surroundings; having to attend group therapy meetings; and having to put up with all the indignities and invasions of privacy that go into being on a psychiatric ward." *Id.* at 112.

fighting and banging her head. In the community, she has none of those problems. She entertains visitors, and sometimes goes to church. She also does her own housework, and has a part-time job cleaning houses. In her own words:

It's better living in my house [than in the hospital] It's much better, because you have staff 24 hours a day like in the hospital but you can go to the bank, shopping, or Rite-Aid. It's better out here. It feels like you're in your normal home. You can't live in the hospital all your life.¹⁷

Asked to name the main advantage of life in the community over life in the hospital, she responded, "I like having the power over my own life."¹⁸

F. Charles Q.

Charles Q. experienced a drastic change in his daily routine when he began to receive community services. Charles was a patient in a Pennsylvania state hospital for some 40 years. Charles has mental retardation and, according to advocates who helped secure his release into the community, he entered the hospital after an extended period of living in a car.¹⁹

Hospital staff administered large doses of the medication Thorazine, which had an adverse affect on his ability to communicate. After a year in the hospital, he became incontinent and nonverbal. He was eventually transferred to a

¹⁷ Telephone interview with Margaret Donahue (Feb. 10, 1999).

¹⁸ *Id.*

¹⁹ Telephone interview with Diana Carra Haugh, Advocacy Specialist at Pennsylvania Protection and Advocacy, Inc. (February 11, 1999).

back ward. There is very little in the files over the years about what happened to him. Advocates discovered him in a geriatric ward of the state hospital.²⁰

According to one of his advocates, Charles "had almost no speech, just a few repetitive phrases. He paced constantly, and was not engaged in any meaningful activity. He didn't have a lot of attachments to anyone there."²¹ Charles' daytime activities were routine and unchanging for most of the forty years he spent in the hospital. Each day, Charles would

...get up about 6 or 6:30 in the morning, get dressed, stand in line for medications for 20 minutes or a half hour, and have his breakfast tray brought to the unit. Then he would begin to pace the halls. He might go outside: they were allowed to go outside, if the weather was good, twice a day to smoke a cigarette, sitting on a bench behind the building. Then he would have lunch, on a tray brought to the unit. The afternoon again would be spent pacing the halls, watching TV, sitting somewhere.... At 4 or 4:30 p.m. a tray of dinner, then pacing the halls, watching TV, sitting in a corner of the room not doing much of anything. Then at 6 or 7 p.m. he'd take a shower, pace the halls and then go to bed.

Once in a while recreation would come in and he would agree to take a van ride, and come back. They wouldn't go anywhere, just in the

²⁰ *Id.*

²¹ Telephone interview with Jacqueline Beilharz, Supervisor, Pennsylvania Protection and Advocacy (February 11, 1999).

van to ride around for a while, and drive back to the hospital. His only other contact with the outside world was his sister, who would visit occasionally.²²

In 1997, Charles was released into the community. He is now living in a group home with three other residents. Staff members help him and the other residents learn "daily living" skills while doing for them the things they have not yet learned to do.

The staff have spent a lot of time helping Charles reintegrate into the community, including going to the grocery store, clothes shopping, the movies, the library—things we all do every day but that he hadn't had a chance to do in 40 years. Charles particularly likes to go to the library. For years, no one knew he could read, but he enjoys reading. He is also fully involved in the daily life of his home. He helps cook dinner, and is learning to use the microwave. He can already use all the other appliances. He goes grocery shopping, and is learning to do his laundry. He enjoys music, talking with staff, leisurely strolls around the neighborhood, and various other recreational activities, such as going to parks, restaurants, playing bingo and Jenga.

Most importantly, Charles is now actively participating in his treatment meetings. He shares his preferences, stating the things he likes and does not like to do. By interacting with people in the community, Charles has learned not to swear or tell people to get away from him. He has progressed rapidly in the most integrated setting appropriate for him.²³

²² *Id.*

²³ *Id.*

II. COMMUNITY-BASED SERVICES ALLOW PEOPLE WITH DISABILITIES TO OBTAIN THE MAXIMUM INDEPENDENCE AND INTEGRATION WHILE RECEIVING TREATMENT AND SUPPORT

As the stories above demonstrate, an array of community-based services is necessary to serve people with disabilities in the most integrated setting appropriate to their needs. Not every person with a disability will need all services. Generally, the individual with a disability and their treating professionals create a service plan that is designed to meet the person's needs. Each of the individuals discussed above uses a subset of services.

In contrast to the institution, a much wider variety of services and creativity is possible in the community due to increased staff and many more opportunities for learning through work, volunteering, and community activities. The institution, which is designed for congregate care of large numbers of individuals by smaller staff, is ill equipped to individualize services and provide opportunities for growth. Moreover, these higher quality community-based services are more cost-effective than institutional care because they do not require large overhead costs and people only use what they need.²⁴

²⁴ See Aileen Rothbard, et al., *Service Utilization and Cost of Community Care for Discharged State Hospital Patients: A Three-Year Follow Up Study*, American Journal of Psychiatry, December 9, 1998, at 2, 16 (study of 321 people who were moved to the community from the institution concluded that community-based treatment cost 50% less than institutional care); Richard D. Budson, M.D., *Community Residential and Partial Hospital Care: Low-Cost Alternative Systems in the Spectrum of Care*, 65 PSYCH. QUARTERLY 209 (1994) (in Massachusetts program, per diem costs of each alternative in continuum of community-based services were significantly less than those in inpatient unit, with the most costly community alternative being less than half as costly as hospitalization).

In this section, we describe the array of services in a community-based system of care, rather than an institutional one. We describe general categories of services and then give specific examples. It should be noted that although the categories are general, there is sometimes different terminology to indicate the same service. For example, in some systems, a case manager is referred to as a service coordinator. Here, we give the most common categories and the definitions to explain what we mean by a community-based mental health service system. The institutions that we have experienced typically have a much smaller array of services, often limited to infrequent group or individual therapy and restricted recreational activities (such as a van ride that does not allow us to leave the van or board and card games).

Costs in community treatment facilities were kept down through staffing patterns that maximized care while minimizing costs, and due to the lack of administrative overhead required in hospital setting); Herbert Bengelsdorf, M.D. et al., *The Cost Effectiveness of Crisis Intervention: Admission Diversion Savings Can Offset the High Cost of Service*, 181 J. NERVOUS & MENTAL DISEASE 757 (1993) (documenting considerable cost savings achieved by using crisis intervention services and other community-based services for individuals who otherwise would have been hospitalized).

A. A Community-Based Mental Health System²⁵

1. Treatment: Treatment services are both diagnostic and therapeutic. Generally, they are provided by professionals or trained personnel to evaluate the nature and extent of an individual's disability and to provide help with learning about and coping with the disability. Treatment services may be provided by an individual or as part of a team process.

A list of potential treatment services may include: 1) intake screening, comprehensive evaluation/assessment and treatment planning; 2) medication therapy and monitoring; 3) outpatient counseling (individual, family and group counseling); 4) mobile community outreach and treatment; 5) crisis intervention and stabilization; 6) intensive day treatment; 7) assistive technology.

2. Residential services: Supportive services can be provided as a complement or as part of a range of housing options. Such services should be flexible, increasing or decreasing in intensity based on the individual's needs. Minor home or environmental modifications or adaptive equipment

²⁵ See Center for Mental Health Services, *Mental Health Directory 1995* at vii-ix (listing mental health organizations and program elements); "A Service Development Plan for a Comprehensive System of Public Mental Health Care in Compliance with the Orders of the Court in *Dixon v. Sullivan and Dixon*," July 1991 (Approved and ordered on January 27, 1992, U.S.D.C. for the District of Columbia, Civil Action 74-285 (AR)); Barbara Wright, *What Legislators Need to Know About Mental Retardation and Developmental Disabilities*, National Conference of State Legislatures (Feb. 1990); State of Alabama, Department of Mental Health and Mental Retardation *Five Year Plan FY 93-94 to FY 97-98* at 46-51; K. Charlie Lakin and Mary Hayden, *Final Report to the Health Care Financing Administration: An Evaluation of Implementation of the Medicaid Community Supported Living Arrangements (CSLA) Program in Eight States 22-23* (1996); Beth Stroul, *Crisis Residential Services in a Community Support System: Report on the NIMH Crisis Residential Services Project 6-10* (1987).

can be used to improve a person's residence to allow for community living, safety, security and accessibility.

Some residential options include: 1) group homes; 2) independent apartments; 3) family or foster (also known as family care) homes; 4) semi-independent apartments; 5) board and care residences.

3. Rehabilitation services: Rehabilitation Services are therapeutic activities designed to improve living skills and to assist the person with a disability in realizing their potential for independence and for useful and productive activity, such as work.

Rehabilitation Services include: 1) day programs; 2) psychosocial rehabilitation; 3) educational services; 4) prevocational services; 5) work adjustment training; 6) supported work and transitional employment programs.

4. Support Services: Support services assist the person with a disability in their daily life. They are often used to ensure that people with disabilities can access resources such as entitlement benefits, medical care and related services. These services also can assist a person in developing relationships key to their success and stability in community living. Case management services, in particular, are important in a helping to create an integrated set of services from an often otherwise fragmented array of state and local resources. Support Services include: 1) case management; 2) intensive case management; 3) family supports; 4) social clubs; 5) advocacy; 6) personal care/home health aide; 7) homemaker and chore services; 8) peer support/self-help group; 9) respite care.

As previously noted, a plan is created from the array of services. For example, named plaintiff L.C. receives several community services to meet her needs. L.C. resides at Nyasha House, a group home which provides intensive support and trained staff who counsel L.C. when she becomes frus-

trated. Staff have found innovative ways to help her deal with these feelings. L.C. also receives psychotropic medications daily. On Monday, Wednesday, and Friday mornings, she attends Community Friendship, which is a day program where she has been receiving educational services and has worked in a supported environment. She has made frequent trips to the library and the homes of staff, and has had other opportunities to interact with the community.²⁶

III. THE PROFESSIONAL LITERATURE CONFIRMS THAT COMMUNITY-BASED MENTAL HEALTH SERVICES ALLOW FOR MORE SOCIAL INTERACTION WITH NON- DISABLED PEOPLE, BETTER RECOVERY, AND GREATER HAPPINESS AND FULFILLMENT.

The professional literature establishes that individuals such as L.C. and those whose stories are told above achieve better outcomes in the community. First, professional literature reflects the view that providing services in community settings is critical to fostering social integration because such settings provide opportunities for individuals with disabilities to develop social relationships and to engage in activities with people without disabilities. These opportunities cannot arise in an institutional setting. Dr. William A. Anthony, Executive Director of the Center for Psychiatric Rehabilitation at Boston University, notes that:

[To achieve] recovery, people need to learn new skills and be provided with appropriate supports. The hospital setting impedes the learning of skills that are needed in the community and, by definition, the community

²⁶ Elliot eval., Exh. 14, R59 (Plaintiffs' Statement of Material Facts with Motion for Summary Judgement, filed 8/19/96).

supports that are needed can't be provided within the hospital. These community supports are essentially people, places, things, and activities²⁷

In addition, community services are virtually always more effective than institutional services in terms of outcomes achieved. Studies show that non-institutional care had better outcomes in almost every case concerning employment, school attendance, and other factors.²⁸ In addition, in-

²⁷ Telephone interview with William A. Anthony, Ph.D. (Feb. 25, 1999). See also William A. Anthony, *Recovery from Mental Illness: The Guiding Vision of the Mental Health Service System in the 1990s*, 16 PSYCHOSOCIAL REHABILITATION J., APRIL 1993, at 11 (mental health recovery requires not just mental health services but other activities such as participation in sports, clubs, adult education, and church activities); Barbara Wright & Martha P. King, National Conference of State Legislatures, *Americans with Developmental Disabilities: Policy Directions for the States* 21 (Feb. 1991) (community living benefits individuals with disabilities by permitting increased independence, sense of competence, improved relationships with family and friends, and increased respect, dignity, and sense of belonging); Paul J. Carling, RETURN TO COMMUNITY: BUILDING SUPPORT SYSTEMS FOR PEOPLE WITH PSYCHIATRIC DISABILITIES 255 (1995) (providing supportive services within integrated community settings and ensuring that consumers have opportunities to engage in "normal" social interactions enhance social integration); Zana Marie Lutfiyya, Center on Human Policy, *Reflections on Relationships between People with Disabilities and Typical People* (Aug. 1988) (enforced segregation in large congregate facilities reinforces the idea that people with disabilities are too "different" to contribute to society, and reduces opportunities for enhancing social integration through social relationships, diversity of social connections, and intimacy in relationships).

²⁸ A. Kiesler, *Mental Hospitals and Alternative Care: Noninstitutionalization as potential Public Policy for Mental Patients*, 37 AM. PSYCHOLOGIST 349, 357-58 (Apr. 1982).

dividuals discharged from state institutions show significantly improved functioning and behaviors.²⁹

Finally, individuals who use mental health and mental retardation services overwhelmingly prefer community-based services to institutional services. As Dr. Anthony notes, "[t]he preference studies indicate that psychiatric patients prefer to live in the community rather than the hospital, so you have a much better motivational base for interventions, because the people are in the spot they prefer. It's hard to do helpful interventions when the person is not in the spot they wish to be in."³⁰

²⁹ James Conroy et al., *A Matched Comparison of the Developmental Growth of Institutionalized and Deinstitutionalized Mentally Retarded Clients*, 86 AM. J. MENTAL DEFICIENCY 581 (1982) (individuals discharged from state institution to community placements showed significantly improved functioning and adaptive behavior after two years). Paul J. Carling, *Major Mental Illness, Housing, and Supports*, 45 AM. PSYCHOLOGIST 969, 971 (Aug. 1990) (studies indicate that "community-based treatment is virtually always as effective or more effective than hospital-based treatment in helping people with psychiatric disabilities to achieve employment outcomes, to gain re-entry into the community, and to reduce the use of medication and outpatient services.").

³⁰ Telephone interview with William A. Anthony, Ph.D. (Feb. 25, 1999). See also Aileen B. Rothbard & Eri Kuno, *The Success of Deinstitutionalization: Empirical Findings from Case Studies on State Hospital Closures*, J. INT'L LAW & PSYCHIATRY, January 28, 1999, at 3-4; Te-wei Hu & Jaclyn W. Hausman, Institute for Mental Health Services Research Working Paper No. 4-94, *Cost-Effectiveness of Community-Based Care for Individuals with Mental Health Problems* 26 (July 1994) (individuals in community-based programs reported higher satisfaction and improvement of quality of life); John Lord & Alison Pedlar, *Life in the Community: Four Years After the Closure of an Institution*, 29 MENTAL RETARDATION 213, 219 (1991) (virtually all individuals in study, who had been moved from institutional setting to group home four years earlier, were happier in community); Paul J. Carling, *Major Mental Illness, Housing, and Supports*, *supra*, at 971 (research indicates that people with

The professional literature reflects the conclusions of the stories herein and the experiences of amici. All people want to live in homes, to be productive and to engage in meaningful activity. When such opportunities are provided in community-based settings, individuals with disabilities achieve better outcomes, have more interaction with people who do not have disabilities, and are generally happier and more fulfilled.

CONCLUSION

The people whose stories are told above are only a few of the individuals whose lives will be affected by the outcome of this case. The ruling in this case will determine whether the states can continue to segregate people in institutions—people who are capable of living successfully in the community—and to deprive them of the freedom to control their own lives. The ruling will also determine whether the Americans with Disabilities Act—the landmark civil rights statute for people with disabilities—gives people who have disabilities meaningful and equal opportunities in their daily lives, or whether these opportunities will be rationed. Finally, this case will decide whether a civil rights statute, similar in intent to the Voting Rights Act, the Fair Housing Act, and the Civil Rights Act of 1964, will be enforced equally across the country, or whether individual states can decide how many civil rights should be accorded to a minority population that has suffered historic discrimination.

In consideration of the serious issues at stake, this Court should affirm the Court of Appeals, on the ground that people with disabilities have a right to the same basic freedoms as all other citizens.

psychiatric disabilities value independence and productivity more than any other treatment outcomes).

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